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HEALTH

As the pandemic enters its 4th year, there's still much to learn about long COVID

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Researchers estimate at least 65 million people worldwide have suffered from long COVID. NPR's Steve Inskeep talks to Dr. Eric Topol about a paper he co-authored on what we know about long COVID.

STEVE INSKEEP, HOST:

Dr. Eric Topol has been studying one of the toughest problems of the pandemic - long COVID, people who suffer for months or years instead of days.

ERIC TOPOL: Because it's varied, because there's a diverse - almost every organ system in the body can be affected, there's unwillingness to understand this picture.

INSKEEP: Researchers estimate that at least 65 million people worldwide have suffered from long COVID. They may report heart problems or blood clots, fatigue, trouble breathing, autoimmune disorders, even diabetes. Diseases that tend to affect older people strike people under 40.

TOPOL: There's been many who - in the medical community who have been trying to deny long COVID's existence because we don't have a simple blood test to make the diagnosis like we do for many other clinical conditions. And eventually we will have such a test. But right now, of course, this is all a work in progress.

INSKEEP: Dr. Topol led some of that work in progress. He's a professor of molecular

medicine at Scripps Research. For the journal Nature, he co-authored a study of studies gathering the available literature to help document long COVID and think through what to do about it.

TOPOL: There are many studies now to show that in some people with long COVID, they have reservoirs of the virus. That is, they have remnants of the virus or even intact replication-competent virus in the gastrointestinal tract or other parts of the body. So they are harboring the virus as a trigger to promote more inflammation, more immune response. And so that isn't necessarily in all people with long COVID, but it has been documented in many. And also it's of interest that one of the drugs we use to treat COVID, Paxlovid, has, in many case reports, helped people with long COVID. And that might be tied into those people who still have a reservoir of virus in their body.

INSKEEP: What are other approaches to treatment?

TOPOL: Well, no treatment has been validated to be effective yet. And so in our review, we list, you know, the many candidate treatments that can be pursued with definitive trials - everything from pacing to try to have the amount of physical activity modulated to hyperbaric oxygen chambers, to ganglion blocks, all sorts of different drugs, apheresis of the blood. There's many different treatments, some of them relatively practical, some of them very inaccessible, expensive. But they need to be assessed because so many of these people are in a desperate, disabling condition. These are people who previously were healthy, often, you know, quite athletic and now incapable of their daily life activity.

INSKEEP: Is this correct that you produced this paper with people who have long COVID?

TOPOL: Yeah, this is something, you know, I'm especially proud of because when the journal asked for a comprehensive review, I turned to three people who I think are the most extraordinary leaders in the long COVID space, who actually each have long COVID. They know it personally, and they have been studying this to try to come up with better treatments, better understanding of long COVID. So, you know, Hannah Davis, Lisa McCorkle, Julia Moore Vogel are exemplary researchers who I had the privilege to work with.

INSKEEP: How, if at all, do you think it shaped your findings that you were working

with people who are experiencing this themselves?

TOPOL: Well, we don't have enough respect for patients themselves with a condition where you learn from them. And I think this is - perhaps the best way is to have people who are much more familiar with how this virus can affect individuals with objective review of the literature and, of course, the peer review system so that it's not written by people who don't really know the condition.

INSKEEP: Is this a case where the patients, in effect, have known more than the doctors?

TOPOL: There isn't any question of that. Unfortunately, today, too many people who have bona fide long COVID, who are suffering - they'll go to a doctor, and the doctor will just dismiss it. And where there are long COVID clinics, they're oversubscribed and hard to get in. So the lack of the medical communities dealing with this inconvenient truth - we have to get over that. We've got to support these folks. We've got to come up with better treatments. And what can't be emphasized enough - there's only one way of preventing long COVID, which is not to get COVID in the first place. And that's another reason not to let our guard down as the pandemic and the virus continues its course.

INSKEEP: Eric Topol, thanks so much.

TOPOL: Thank you, Steve. Great to talk with you.

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